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Experiences, Views, and Support Needs of Family Members of People With Hypoglycemia Unawareness: Interview Study

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OBJECTIVE

Hypoglycemia unawareness (HU) affects ~25% of people with type 1 diabetes. People with HU are often reliant on family to detect hypoglycemia and treat severe episodes. We explored the impact of HU on family members' lives, their involvement in preventing and managing hypoglycemia, and their information and support needs.

RESEARCH DESIGN AND METHODS

This study employed an exploratory, qualitative design comprising in-depth interviews with 24 adult family members of persons with type 1 diabetes and HU.

RESULTS

Family members described restricting their lives so that they could help the person with HU detect and treat hypoglycemia. Some described being very physically afraid of their partner/relative when they had a hypoglycemic episode due to their aggressive and argumentative behavior and personality changes; this could also make treatment administration difficult. Family members also reported feeling anxious and worried about the safety of the person with HU, particularly when they were left unsupervised. These concerns were often precipitated by traumatic events, such as discovering the person with HU in a coma. Family members could neglect their own health and well-being to care for the person with HU and resentment could build up over time. Family members highlighted extensive, unmet needs for information and emotional support; however, some struggled to recognize and accept their own need for help.

CONCLUSIONS

Our findings reveal a caregiver group currently "in the shadow of the patient" and in urgent need of information and emotional support. Raising awareness among health care professionals is essential, and developing proactive support for family should be considered.

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Hypoglycemia unawareness (HU) is a term used to describe the phenomenon whereby people with diabetes no longer experience the symptoms that warn them of hypoglycemia (1). It carries a sixfold increase in risk of severe hypoglycemia episodes, which are associated with confusion, coma, and seizure and which individuals are unable to self-treat (2). While the extent of HU varies, some degree of unawareness affects ~25% of people with type 1 diabetes, with the proportion rising to almost 50% among those diagnosed for >20 years (3).

Neuroimaging studies suggest that HU may be associated with altered activation in brain regions involved in reward responses during hypoglycemia (4,5), which might impede treatment adherence in those affected by the condition (6). Such treatment barriers have been observed in an interview study with adults with type 1 diabetes affected by HU (7). Despite experiencing frightening, disabling, socially embarrassing, and dangerous episodes of severe hypoglycemia, more than half of those interviewed expressed a lack of concern and poor motivation to adopt hypoglycemia avoidance strategies. Participants also highlighted their dependence on family members to minimize the risks and effects of hypoglycemia (7).

While the role of family members in moderating and normalizing the disruptive effects of illness is well recognized clinically (8) and research suggests that the quality of a marital relationship can affect diabetes adaptation (9), very little is known about the experiences and support needs of family caregivers of people who have HU. Recent qualitative work undertaken with spouses of people with type 1 diabetes suggests that anxiety about hypoglycemia can be a source of partner and marital distress (10); however, this study did not focus on caregiver issues relating to HU. Quantitative work undertaken with spouses of people with type 1 diabetes found increased fear of hypoglycemia and marital conflict about diabetes among those recently exposed to severe hypoglycemia, leading the authors to recommend that increased empirical and clinical attention be given to family members (11).

To understand their experiences better, we undertook an interview study with partners/family members of people with type 1 diabetes with established HU or recurrent severe hypoglycemia. Key study aims were to explore the impact of HU on family members' own lives, their involvement in the prevention and management of hypoglycemia, and whether, and in what ways, they could be better supported or helped to support the person with HU.

RESEARCH DESIGN AND METHODS

Qualitative methods are recommended when little is known about the area of investigation, as they allow findings and themes to emerge from the data rather than testing predetermined hypotheses (12). Interviews, informed by topic guides, were used to enable the discussion to stay relevant to the study aims while allowing participants to raise issues they perceived as salient. Data collection and analysis took place simultaneously, in line with the principles of grounded theory research (13), enabling issues identified in the early interviews to inform the areas explored in later ones.

Recruitment and Data Collection

Family members were recruited via people with type 1 diabetes who had been approached to participate in a qualitative investigation of a pilot clinical intervention (the DAFNE-HART study) for people with HU or recurrent severe hypoglycemia conducted in two secondary care diabetes centers in the U.K. (14). Participants were asked if they could identify a partner or other adult family member who helped them detect and manage hypoglycemia. Those who identified an eligible person were given a study information pack, which included an opt-in form. Family members who returned their opt-in forms were contacted to arrange an interview. Interviews averaged an hour and were digitally audio recorded and transcribed in full for in-depth analysis. Recruitment stopped when no new findings were identified in new data collected. Interviews were conducted in July and August 2012.

Data Analysis

Two experienced qualitative researchers (J.L. and D.R.) undertook

data analysis. A thematic analytical approach was used in which transcripts were cross-compared (15) to identify issues and experiences that cut across different people's accounts and the underlying reasons for similarities and differences in their experiences and views. J.L. and D.R. first examined the data independently and wrote separate reports before meeting to compare interpretations and reach agreement on key findings. Once agreement had been achieved, a coding framework was developed to capture key themes, and each coded theme was subjected to further analysis to identify subthemes and illustrative quotes. NVivo, a qualitative software package, was used to facilitate data coding/retrieval.

Research ethics approval was granted by the National Research Ethics Service, Kings College Hospital Research Ethics Committee (08/H0808/53). For protection of family members' anonymity, unique identifiers are used below (e.g., R1, R2, etc.).

RESULTS

Of 30 family members approached, 24 opted into the study, and all were interviewed. The final sample comprised 18 partners, 3 parents, and 3 adult children. Demographic characteristics of the sample are presented in Table 1.

Monitoring and Supervision: Restricting One's Own Lifestyle

All family members described how, owing to their partner/relative's own difficulties detecting low blood glucose levels, they needed to monitor them for early signs of hypoglycemia. As these signs were often very subtle, such as the person with HU "not quite saying a word correctly" (R1), going "glass eyed" (R14), or there being "just the slightest change in the inflection of her voice" (R13), monitoring activities were described as requiring high levels of vigilance and for family members to be constantly alert. As a consequence, most family members had curtailed their own activities and lifestyles. This included giving up recreational activities that took them out of their homes, "I just don't have a social life" (R1), cancelling or not taking holidays, going into work late, or, in extreme cases, turning down

Table 1—Demographic characteristics of 24 adult family members

	Relationship of participant with person with diabetes*		
	Spouse/partner	Parent	Adult child
<i>n</i>	18	3	3
Female sex, <i>n</i> (%)	12 (66.6)	3 (100)	2 (66.6)
Age (years), mean ± SD, range	51.4 ± 11.2, 26–72	60.7 ± 10.1, 49–66	25.7 ± 6.0, 20–32
Living with person with diabetes, <i>n</i> (%)	18 (100)	2 (66.7)	0
Person diagnosed with diabetes before beginning relationship, <i>n</i> (%)	12 (66.7)	N/A	N/A
Married (yes), <i>n</i> (%)	15 (83.3)	N/A	N/A
No. of years married, mean ± SD, range	24.7 ± 11.1, 5–49	N/A	N/A
Occupation, <i>n</i> (%)			
Professional (health, education, etc.)	6 (25)		
Semiskilled (office worker)	5 (20.8)		1 (4.2)
Unskilled	3 (12.5)	1 (4.2)	
Student			1 (4.2)
Retired	2 (8.3)	2 (8.3)	
Unemployed	2 (8.3)		1 (4.2)

*None were related to the same person with diabetes; all were white British.

employment or postponing elective surgery. As family members also observed, pressures to curtail activities could also come from the person with HU, due to them feeling vulnerable and scared when left unsupervised.

Concern about the safety of the person with HU was an additional reason presented by family members for restricting and changing their own lifestyles. Such worries were often precipitated by traumatic events, such as returning home and finding their partner/relative having a seizure or lying unresponsive on the floor or, in R1's case, when her son was discovered at work, unconscious, "propped against a window on a stairwell that was abandoned." As a result of this very distressing incident, during which she believed her son could have died, this mother reported spending about "ninety-five percent" of her time worrying about him. Similar levels of concern were conveyed by others, such as R14, who described how "there's not a minute which goes by when I'm not thinking, what's happening?" and R8, who described being "perpetually worried" after finding her partner in a comatose state.

Hence, to help address their worries and concerns, family members described

using systems such as frequent texting or making regular phone calls when the person with HU was left or went out alone (e.g., to work). Other surveillance strategies were also reported, such as encouraging a child with HU to purchase a property near to the parental home or enlisting the help of others: "We say to the neighbors, if the curtains don't open, you know, can you, you know, call or what have you so that someone can go and let themselves in and see if she's okay?" (R17). Hence, even when they were physically remote from the person with HU, family members reported little respite from their supervisory roles and responsibilities.

Dealing With Hypoglycemia: Fear and Worries About Safety

The challenges family caregivers reported extended well beyond needing to help detect hypoglycemia and check that their partner/relative was safe. Family members also talked at length about the physical and emotional difficulties they could encounter when they attempted to help the person with hypoglycemia treatment, due to cognitive changes arising from low blood glucose levels. These changes ranged from their partner/relative being "quite silly and giggly" (R7) to them

being "very aggressive and argumentative" and "violent" (R21). As a consequence, family members described how they could struggle to keep their own frustrations and emotions in check: "If you brought her [wife] a glass of milk, she might hit it out of your hand, so that would immediately make you a bit, well, might make you a bit angry at times" (R5). Others, typically older or female caregivers, reported being very physically afraid when their partner/relative was having a hypoglycemic episode. This included a woman in her 70s who described her sense of physical and emotional vulnerability when her otherwise kind and gentle husband experienced mood and behavioral changes after his blood glucose levels started to go low:

He refuses the drink, and he gets quite, very angry and agitated and, and I do kind of, I can see myself when he's had them being very careful not to let him grab me because his strength is huge at that point and I know I'm small, I'm five foot one, and he's six foot two. I do get physically afraid on those instances and just won't let him take my hand. (R10)

Another female caregiver, likewise, reported having had to develop "hands off" strategies to protect their own safety:

He [husband] has been known to be very violent and bite me and hit me and at one point I must admit if he did ever have a hypo in the night it used to frighten me that much that when I knew there was nothing else I could do for him I used to find it easier to just put a pillow behind him and a pillow in front of him and roll him into the middle of the bed so that I'd know he was safe and then I used to like just wait at the door. (R11)

Concerns about safety could also extend to children and grandchildren, with R15, for instance, recounting a traumatic incident when her husband had a hypoglycemic episode while driving that had resulted in her being "constantly on alert, frightened, and apprehensive"

every time he now took their children out in the car:

We've all been in the car and he's becoming increasingly [hypoglycemic], with blood sugars dropping very rapidly and I'm trying to get him to pull over and he's just been laughing and shouting and, and, and that's been very scary and what actually ended up happening in that particular situation is that me and the children were all screaming and crying more loudly than [my husband] and something must have got through to him and he pulled over.

As well as worrying about safety issues, family members also described the upset and distress that could result from witnessing the audio and visual changes that could accompany severe hypoglycemia. R5, for instance, recounted an incident from her childhood, when she observed her mother being taken out of the home on a stretcher by an ambulance crew and which she described as having had a long-lasting psychological impact: "She was staring at me, like she has these eyes, her face just looked so scary to me as a young child, and I just remembered this face. It was horrible to see that, I still remember it vividly to this day" (R3).

Others used possession and demonic metaphors to convey the distress and fear they experienced when they observed or heard a hypoglycemic episode: "It was like the cry of the banshees, a great big wail and a grand mal type fit" (R20); "We hear the bed rattling, she makes these most unearthly noises" (R17); "It's like you're fighting this demon, it's like someone had taken your wife away" (R21).

Physical and Emotional Impact of Caring for a Person With HU

Exhaustion; Neglecting One's Own Health and Social Needs

Family members described periods of extreme exhaustion, particularly when they had to deal with regular occurrences of nocturnal hypoglycemia. Several ($n = 6$), for instance, reported very poor, interrupted sleep owing to their worries that the person with HU would slip into a coma or exhibit violent behavior toward them during the night:

I find myself sleeping on the edge, feeling I may be woken at any minute, and if I wake, any change in breathing, I'm alert, checking on him . . . I would wake up just because he has turned strangely or changed his breathing and then I'm secretly trying to make sure he's all right. (R10)

Similarly, R17, whose adult daughter still lived at home, described always keeping her bedroom door open and making regular nighttime checks to reassure herself that her daughter was safe and alive owing to her constant worry that she could wake up one morning and find her dead in bed.

The requirement to constantly supervise the person with HU and offer prompt treatment when hypoglycemia occurred often meant that family members had neglected or ignored their own health and social needs: "I feel [HU] does take over because you've always got to be thinking about someone else other than yourself. I sometimes just think I need, like, you know, a day or two where I don't have to think about anyone but myself and I just don't ever get that" (R18). In some cases where the family member had been living with the person with HU for many years, extreme burnout and fatigue was also apparent: "But I'm exhausted with worrying about him and everything is just flat now. It's like a flat feeling of, of everything. That's why I'm finding it difficult to talk about it, I think because deep down, I'm, I'm just flat, sad, resigned" (R20).

Resentment and Ambivalence

A minority of partners ($n = 3$), all of whom who had formed a relationship after their spouse had developed HU, were keen to present themselves as having taken on their caring roles willingly and knowingly: "It's . . . my calling in life to look after [partner]" (R5); "It's a partnership, you know, we're both there for each other, no matter what it is" (R16). However, many ($n = 15$) conveyed an outward and growing sense of resentment resulting from the stresses HU placed on their own lives and also how it affected the dynamics of their relationship with their partner/relative. Family members, for instance, reported disliking having to adopt parental or bullying roles in order

to persuade the person with HU to check their blood glucose levels or take treatments: "I end up shouting until he pays attention. It's horrible because I feel like I've a third child" (R15, wife). Others, too, highlighted unwanted changes resulting from the person with HU losing self-confidence, and, hence, becoming a different person from the one they had chosen to enter into a relationship with: "I feel guilty. I'm not the kind of character that finds joy in mothering another adult that I loved and respected as a male, you know, responsible being. I'm not, I want a proper partner" (R20).

While, in general, the person with HU was not seen to be to blame for their condition and its effects, patients were sometimes accused of being selfish for maintaining tight blood glucose control and thereby putting their own long-term health in front of the more immediate safety and well-being of others, such as their children. Some family members ($n = 6$) also speculated—and resented—that they were used unduly as a safety net by noting that, on occasions when they did go away (e.g., on holiday), the person with HU was more likely to use preventative measures, such as allowing temporary elevation of their blood glucose levels: "As soon as we get home and she relaxes she nearly always has a hypo that day or that night" (R17).

Family members, however, could also struggle to come to terms with feeling angry and resentful, since, as they explicitly recognized, the person with HU experienced an impaired cognitive state when they had hypoglycemia and, hence, could not be held responsible for their actions. For this reason, R15 likened her situation to being with:

an abusive partner who hits their wife and then, as they kind of sober up, they're sort of full of remorse and they can't believe they've done it . . . it's the same for [husband's name] but he's actually done nothing wrong. So, I can't be angry 'cause that's not fair.

Additional problems conveying, and reconciling, how they felt could also result from family members'

observations that the person with HU was unable properly to recall their hypos and accompanying behavior, and, hence, had little insight into what they had just put others through:

A hypo's a weird thing because then, you know, like, when it's all over, it's just like, "Ha, okay, let's, that was, that episode's all finished, let's carry on" sort of thing. . . . It's not an event for her but we're all sort of, like, standing there shaking and she's like, "Oh I feel better," sort of thing. (R21)

Education, Information, and Support Needs

Most family members ($n = 15$) indicated a lack of understanding and support from friends and distant relatives. However, the greatest (perceived) lack of support came from health professionals, with only two able to point to instances where they had been asked (either by diabetes health care professionals or their own family doctor) how they were coping and if they needed help: "No, nobody has ever asked me anything. . . . I feel disappointed" (R9). Indeed, some ($n = 7$) spontaneously described the research interview as the first time they had ever been invited to talk about their own experiences and needs.

A key concern raised by family members was that they had to rely on knowledge passed onto them by their partner/relative about hypoglycemia treatment and that they "might not have relayed everything to me" (R14). Family members also shared their concerns about using glucagon injections without having received health professional instruction, with some ($n = 6$) being too frightened to administer them as a consequence. Alongside educational deficits, family members described having felt emotionally ill prepared for the behavioral and personality changes that could accompany hypoglycemia. They also highlighted a need to develop a better understanding of the physical impact of hypoglycemia on their partner/relative to be able to offer them more empathetic support.

To address their unmet needs, almost all family members ($n = 20$) indicated a

requirement for more information and education, with some ($n = 7$) also wanting the opportunity to accompany the person with HU to their diabetes consultations. This was not only to receive instruction and advice from health professionals but also because they were worried that, due to poor recollection, the person with HU might be underreporting episodes of severe hypoglycemia. Alongside education, most ($n = 19$) described needing reassurance, feedback, and emotional support from people in the same situation as themselves to help overcome their feelings of isolation, resentment, and sometimes guilt. (Indeed, several looked to the interviewer for reassurance that they were not alone in experiencing negative feelings.) Peer support was also highlighted as a potential means of accessing and sharing tips on how to manage behavioral and personality changes in "real-life" situations. While most family members highlighted a need for a support group, they also suggested that they could learn about others' experiences via "some kind of Web site where partners, you know, post their experiences" (R22). All family members who described needing support also emphasized the need for a dedicated forum for themselves to allow them to share negative feelings and experiences.

There was, however, a distinct minority ($n = 6$) who, despite articulating difficulties during their interviews and highlighting information needs, struggled to acknowledge either their own need for or their right to support. This included R15, who, despite earlier likening her own situation to "being with an abusive partner," went on to state, "I still feel very much like the person who has the illness is the person who needs the most support," and R8, who said:

I never labor on it with my friends 'cause . . . I've got a body and a pancreas that works and I think that it, it would, I would, almost, feel, feel guilty talking to my friends and saying, that it's, that it's difficult because it is difficult but, it's, it's a hundred times more difficult for [partner's name].

CONCLUSIONS

While the impact of hypoglycemia on the diabetes management and quality of life of people with type 1 diabetes is well documented (16–20), much less is known about its effects on families. By using an open-ended, exploratory qualitative design, we have identified a caregiver group currently "in the shadow of the patient" (21) who urgently need more information and emotional support. As highlighted in this study, the impact of hypoglycemia unawareness and resulting hypoglycemia can extend well beyond the person with HU, with all family members describing how they had had to restrict their own lives to help with detection and treatment. All family members also reported feeling anxious and worried, with these concerns having often been precipitated by distressing events, such as finding the person with HU unconscious on the floor, or having been exposed to argumentative, aggressive, and sometimes very physically threatening behavior. Behavioral and personality changes were also described as making treatment administration very stressful and difficult. Some family members described outwardly resenting the impact that HU had had on their own lives, health, and well-being and on the dynamics of their relationship with the person with HU. While family members highlighted extensive unmet needs for information and emotional support, some struggled to recognize or accept their own need for, or right to, help.

Given the issues raised in this study, it is clear that clinical effort should continue to be directed toward diagnosing HU and offering effective interventions to help patients restore awareness of hypoglycemia (22). Arguably, future interventions should also include family members, as others have also recommended (10), since family can play an instrumental role in helping with hypoglycemia detection and treatment. While interventions to restore awareness of hypoglycemia would help reduce the burden and stress that family members experience, family caregivers would also benefit from tailored support to help address their unmet emotional, practical, or informational needs. For

instance, to address family members' need for support from people in the same situation as themselves, dedicated support groups could be set up within hospital diabetes clinics or other settings, which could also include questions and answer sessions with health professionals. The development of online resources, coordinated and facilitated by knowledgeable and trained personnel, could also be considered. These could enable family members to share tips and experiences (e.g., via videos and written accounts) as well as to access up-to-date clinical information. Web-based resources have been shown to be well received by people affected by other chronic conditions (23) and, if developed, might also be easier to access than support groups.

However, as some family members struggled to recognize or accept their own need for help, we would also encourage health professionals, such as family members' own general practitioners, to ask, opportunistically, how they are coping during consultations and routine health checks. Furthermore, given family members' concerns that the person with HU may be underreporting their hypoglycemia and the unreliability of patients' reports of hypoglycemia observed in another study (24), health professionals could consider encouraging patients to attend their diabetes appointments with family members and specifically ask them to discuss hypoglycemia problems. They could also use these appointments to help ensure that caregivers are offered education and information about applying hypoglycemia management. Health professionals could also consider extending similar kinds of support to family members of people with type 2 diabetes using insulin or sulfonylureas, as these individuals are also vulnerable to HU and associated problems (25–27).

Study Limitations and Recommendations for Future Research

This study has identified a caregiver group who would clearly benefit from greater support, and to achieve this, raising awareness among health professionals is an essential first step. However, because the study was necessarily small-scale and the family

members who took part were those of people with documented recalcitrant problematic hypoglycemia, the potential generalizability of the findings may be limited. In addition, we did not interview children aged <18 years, who may have different, and age-specific, information and support needs. Hence, further research, including a large-scale, quantitative study, could be conducted to better establish the full nature and extent of the problems identified in the current study. Such a study could quantify the levels of anxiety, stress, depression, and caregiver burden experienced by family members of people with HU, possibly drawing on the earlier work of Gonder-Frederick et al. with spousal caregivers (11). Future research could also collate useful strategies used by family members to help the person with HU and identify the support needs of family members aged <18 years.

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critical revisions to the paper, and approved the final version. J.E., S.R.H., H.A.R., N.D.Z., and S.A. contributed to the study design, helped with the development of the interview topic guides, were involved in making critical revisions to the manuscript, and approved the final version. J.L. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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